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ABSTRACT

This compilation of position statements of the Association for Retarded Citizens (ARC) describes what the Association believes on critical issues related to rights, treatment, services, and programs for children and adults with mental retardation and their families. This publication contains positions that the Board of Directors of ARC of the United States agreed, in 1988, should remain in force as written and those new and/or revised that were approved by the ARC's Delegate Body in 1989 and 1990. Specific position statements address the following topics: the rights of people with mental retardation, quality assurance, family support, individual service coordination (case management), integration, self-advocacy, sexuality, education, employment, residential living arrangements, behavior intervention, guardianship, and prevention of mental retardation. (JDD)

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Position Statements

of the

Association for Retarded Citizens of the United States

arc
Association for Retarded Citizens

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PREFACE

Over the years, the Association for Retarded Citizens has developed position statements addressing various issues related to rights, treatment, services and programs for children and adults with mental retardation and their families. The Association's positions describe what the ARC believes on critical issues. They are used to guide ARC local, state and national officers, staff, committees and members in planning, operating and evaluating programs as well as in making public statements. The consistent use of these positions throughout the Association enables the ARC to function effectively as one voice. Our positions have also frequently had a significant impact on the development of legislation and programs in our nation.

In 1988, the Board of Directors of ARC of the United States reviewed existing positions and voted to revise or rewrite many of them. The Board also identified areas that required new positions. This publication contains positions that the Board agreed should remain in force as written and those new and/or revised that have been approved by the ARC's Delegate Body in 1989 and 1990.

The ARC will continue the process of rewriting positions and developing new ones as needs arise on an annual basis. We recognize that as change occurs constantly, all of these positions need to be reexamined and, as needed, changed. It is our hope that members and chapters will individually and collectively use these positions continuously and in the process identify needed changes. We value your comments and assure you they are always welcome.

The ARC is especially indebted to Barbara Sackett who, as President of ARC of the United States, initiated this process of annual review, revision and writing of position statements during her term as President. It is also indebted to Colleen Wieck, Ph.D., who as chair of the ARC's Program Services for Children and Adults Committee, managed the process of updating ARC's positions. Finally, appreciation must be extended to the members and staff from many ARC state and local chapters who, after careful consideration, provided thoughtful comments that ultimately led to the position statements that have been adopted.

James B. Gardner, President
ARC of the United States
1991

PREAMBLE

The needs that led to the establishment of the Association for Retarded Citizens, and as articulated in its original constitution in 1950, have not changed. This is expressed today in the form of a Mission Statement as follows:

> *The Association for Retarded Citizens, the ARC, is committed to securing for all people with mental retardation the opportunity to choose and realize their goals of where and how they learn, live, work, and play.*
>
> *The ARC is further committed to reducing the incidence and limiting the consequence of mental retardation through education, research, advocacy and the support of families, friends and community.*
>
> *Through the successful pursuit of quality and justice, the ARC will provide leadership in the field of mental retardation and develop necessary human and financial resources to attain its goals.*

What is changing, however, and will continue to change, are our concepts of how this mission can best be accomplished.

In the past 40 years, the Association has confronted a number of challenges not anticipated at its founding. To guide the action of its members and leaders on every level of the organization, explicit policies are required that interpret its broad purposes in a specific, contemporary frame of reference. In clarifying its program policies on behalf of people with mental retardation and their families, the Association bases its positions on certain underlying and value-based assumptions or principles. The purpose of this preamble is to describe several key principles and to show their relationship to the evolving system of knowledge, values and beliefs that ARC members should share with the larger community.

During the past four decades there has been extraordinary progress in the biological, environmental, behavioral and social sciences. The nature of memory, the processes of learning, the roles of neuro-transmitters and synapses in the brain are better understood. Many of the critical roles of genes and chromosones in the causation of certain disabilities have been identified. The positive and negative effects of architectural design on human motivation and performance are now better appreciated. New technologies have been successfully applied to augment communication and facilitate mobility among people with impairments of these natural functions.

The fact that this preamble is being rewritten only five years after the first compilation of ARC position statements, attests to the rapid changes in our knowledge base which brings a new and wider frame of reference for our beliefs and assumptions. Changing these beliefs, however, may be a slow process because of an emotional investment in them which can be antithetical to change. Once change is under way, though, it is likely to gain momentum and may exceed the mark.

As members of ARC committed to promoting the well-being of people with mental retardation, we need to make informed decisions. As individuals and as an organization, we must take into account what we know or believe about the people who will be affected by the outcomes. It is imperative to have a basis for our actions. Every day demands that we make decisions and carry on activities that will have consequences for ourselves and for others.

People confronted with this task look for a way to condense their conventional wisdom into aphorisms or code words: "Speak softly but carry a big stick;" "Spare the rod and spoil the child;" "They are better off with their own kind." A decade ago, code words current in ARC circles included "normalization," "continuum of services" and developmental model." Even the terms "independence, productivity and integration" are today being expanded by "self-reliance," "inclusion," "interdependence," "contribution," "participation," and "self-determination." While recognizing each generation's right to coin its own language, we offer a few principles that we believe have proven to be both durable and adaptable in a fast-changing social scene.

Principles and Assumptions

1. Every person is unique, each with his or her own capabilities and limitations. There is immense variability among all people, including people with mental retardation. Yet, we recognize that people with mental retardation are more like everyone else than they are different.

2. People with mental retardation are people first. A disability should receive attention only when it is relevant and always in a respectful manner.

3. Efforts to prevent mental retardation do not demean any individual with this disability.

4. Prejudice, stigma, denial of needed services and other forms of discrimination against persons with mental retardation, singly or in groups, should be fought by all legitimate and effective means.

5. A sense of control over one's destiny is essential. We affirm the right of individuals with mental retardation to have the opportunity to make choices for themselves and to exert a measure of control over their physical and social environment. The community has a responsibility to provide the support that is necessary for people with mental retardation to function successfully as participants in their community and to offer them the opportunity to act and develop as citizens.

In summary, people with mental retardation are citizens with all the rights and responsibilities that accompany citizenship. Encompassed in this right to life, liberty and the pursuit of happiness, is the requirement for equal treatment under the law and full enjoyment of civil rights. Further, we believe that people with mental retardation have the right to individualized services designed to meet their specific needs and help ensure optimal functioning, that services should be provided within the generic system to the greatest extent possible and that full opportunity be given for a meaningful life in the community.

The translation of the foregoing into specific positions applicable to particular situations is not accomplished without analysis and debate. These positions have been subjected to scrutiny and refinement within a democratic process and reflect the views of many participants. While consensus is sought, unanimity is seldom found.

THE RIGHTS OF PEOPLE WHO ARE MENTALLY RETARDED

ISSUE

The fundamental rights of people who are mentally retarded are not yet fully acknowledged or secured, despite the vigorous efforts of advocates to help them achieve the same basic human and constitutional rights as other human beings. There is also the controversial question of whether special rights; protections, and privileges are required or desirable.

Some believe that children and adults who are mentally retarded have a "right" to more services and support than non-handicapped citizens. Because of their handicaps, special services are necessary to allow these individuals to fully exercise their basic rights. Others challenge the validity of this stance in terms of "competing equities." Is it normalizing (and consistent) to demand equal protection and treatment while at the same time pressing for "special privileges?" It is also argued that society simply lacks the resources to provide all of its citizens with the benefits that may be desirable.

A related concern or issue is whether special legal protections should be provided for adults and children who are mentally retarded. One question is the protection of rights through guardianship. (See position statement on guardianship.) Another is the question of providing special legal protections against parental decisions which may run contrary to the child's best interests. These questions become more critical when they arise in situations which involve the placement (e.g., residential, educational or vocational) of a person who is mentally retarded or the withholding of potentially life-saving medical treatment because of perceived severity of the individual's intellectual handicap.

Legitimate differences of opinion may arise between parents and professionals or advocates concerning the courses of action which best protect the interests of a family member who is mentally retarded. One view is that the vast majority of parents actually know their offspring better than anyone else, have their best interests at heart and are in a better position to make critical decisions than professionals or advocates. A second view is that parental decisions may at times run contrary to a child's best interests and persons not intimately and emotionally involved may be in a better position to make important decisions on a child's behalf.

POSITION

The ARC believes persons who are mentally retarded have the same legal, personal, and civil rights under the federal and state laws as any other citizen. These rights, as for all citizens, should never be limited or restricted without compelling state interests and due process.

Persons who are mentally retarded are entitled to the same services and protections as other citizens. Adults should be allowed to fully exercise their citizenship rights and live as independently and normally as possible. When necessary, in light of the nature of their special handicaps, services and protections should include those, similar to those offered to other disadvantaged people, which allow individuals to exercise their rights in a meaningful way.

In accord with this position, the ARC believes that the rights and protections of minor children who are mentally retarded and their parents are no more or no less than those for other children and their parents. The same presumptions pertain in favor of parental obligations and responsibilities to make decisions and act on behalf of their minor children. As with any child, parents of children who are mentally retarded do not have the prerogative to make decisions or take actions which threaten the health or safety or lives of their children. In such situations, the same legal mechanisms -- constitutional, legislative, administrative, and judicial -- which protect the lives and safety of all children should be vigorously and expeditiously pursued.

The ARC strongly encourages the establishment of human rights committees to help ensure the welfare of persons with mental retardation.

Adopted by Delegate Body, 1983
Adopted by Board of Directors, 1984

QUALITY

ISSUE

The rapid expansion and diversification of services for people with mental retardation has led to increased concern about how to define quality and how to assure quality.

In the past, quality has meant compliance with minimal standards such as physical space, staff ratios, written policies and processes. While improving federal and state standards remains a common approach to define and assure quality, we must now confront the more elusive elements of quality.

The Association for Retarded Citizens has always articulated value-based principles such as individualization, respect, dignity, freedom from harm, integration (participation) independence (interdependence) and productivity (contribution). Emphasis on the individual must continue to be the ongoing focal point of quality.

POSITION

The ARC believes that quality must be viewed as a multidimensional concept. We believe that the ARC should work to assure that a multidimensional system for ensuring quality is in place and functioning effectively. Fundamentally, quality begins with the individual with mental retardation in terms of frequent and direct measures of satisfaction and outcomes. All individuals with mental retardation should, through formal and informal interviews or observations, be asked about their satisfaction and preferences regarding services, supports and other aspects of their lives. In cases of people with multiple or sensory impairments, alternative methods of communication should be used.

A second level of quality is the satisfaction of family, advocates and/or friends. In some cases, the views of family, advocates and friends may be in direct conflict with the individual's preferences. In these instances, respect, dignity and protection from harm must be carefully considered in resolving differences.

A next level of assessing quality is to rely on measures of outcomes such as levels of productivity or contributions, integration or participation and independence or interdependence. These measures provide a progress report on how well the individual is doing.

A fourth level of quality is to ask questions about the relevance and functionality of goals and objectives within the individual plan. These questions can be raised during the periodic reviews of individual plans.

Independent case management/ service coordination provides another level of monitoring quality through involvement in the assessment, planning, implementation and evaluation of services and supports for individuals with mental retardation.

The sixth level of monitoring quality is periodic visits and checks by families, friends and advocates on the humaneness of services and supports. This important approach is often called citizen monitoring.

Finally, state licensure, federal certification and national accreditation are traditional means to assure compliance with standards of health, safety and rights.

The ARC must be a catalyst for bringing about a value-based cohesive, consistent and coherent system of quality which better defines the elusive dynamic called quality.

Defining and assuring quality depends on fact finding, interpretation and judgment. How we assure quality depends on how we define quality. By infusing values in all decisions, we will define standards that exceed current professional practice and will require periodic redefinition of "best" practice.

ARC believes that assuring quality is a process that converts evolving values and beliefs into quantitative and qualitative assessments. ARC must advocate for increased empowerment of individuals and families in this process.

Defining quality is a dynamic process. This process is inherently difficult because beliefs must be translated into surveys and instruments. The state of the practice usually lags behind the state of the art.

The process of thinking and caring about quality is essential to achieve quality. For example, the process of seeking and preparing for accreditation may be more important than achieving accreditation. The process of citizen monitoring may be more important than the report of findings. Organizational commitment and actions toward quality actually lead to definition and redefinition of what constitutes quality.

Adopted by Delegate Body
October 6, 1989

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FAMILY SUPPORT

ISSUE

Since its beginning, one of the guiding principles of the ARC is to provide support to families who have a child with mental retardation. The birth of a child with mental retardation may have a profound, often lifelong, effect on a family. In some cases, one or both parents may have mental retardation, thereby presenting unique family needs. Most family support in the United States is provided by relatives, friends and communities. However, while important, these informal supports may not be sufficient in assisting a family in meeting its needs throughout the life of a person with mental retardation. Natural or adoptive, families may benefit from a variety of supports tailored to the families' needs.

An effective response to family needs requires that a comprehensive and flexible array of supports be made available. The ARC recognizes that support of the entire family is often needed to make it possible for individuals to live at home, with the maximum possible independence, or to remain within the family circle if they reside elsewhere.

ARC recognizes that the needs of parents change over time. This ranges from those who are young and struggling to cope with demands of jobs and families to those who are older and trying to plan for their future as well as that of their son or daughter.

ARC further believes that premature out-of-home placement is frequently the result of a failure to provide adequate supports to help a family remain intact, rather than the result of the individual's disability itself.

POSITION

The ARC believes that in most situations, the natural or adoptive family is the best source of support for a child with mental retardation and an important part of life for most adults with mental retardation. Family and individual support should be offered as needed throughout the life of a person with mental retardation. This position is supported by the ARC through parent groups, information and referral networks, and advocacy whenever needed. Advocacy support may be for the individual or family, or it may involve systems intervention or service systems change such as legislation or legal action to support a person's rights. ARC aggressively seeks and advocates for:

- the development of local, state and national policy that has a family-centered approach to supporting people with mental retardation and requires that agencies provide coordinated, comprehensive, affordable and flexible services;

- in-home services to families as needed to provide care and enhance the quality of their lives, including respite care, personal assistance, specialized training and individualized family assistance;

- other support services such as the availability of medical/dental care, health insurance and transportation;

- informal, yet stable, community networks;

- information and training to enable a family to make informed decisions and to serve as the coordinator of services for their family member, if desired;

- evaluation of the impact of and family satisfaction with programs;

- family supports that maximize the family's identification, selection and control over the services they receive;

- family support initiatives that are designed to promote the integration of children and adults with mental retardation into the community; and

- for those people with mental retardation without families, a support network of interested citizens to assure services are received and to assist individuals in exercising their rights and fulfilling their responsibilities.

In addition, the ARC believes that families, siblings and extended family members can be supported by ARC members who have had similar experiences. Families must have information and training to ensure that appropriate services are available. The ARC is therefore committed to the maintenance of a strong network of local chapters throughout the United States.

The ARC will help families advocate effectively on their own behalf and will provide the emotional support and technical assistance needed to improve the quality of life for all family members.

Adopted by Delegate Body
November 10, 1990

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INDIVIDUAL SERVICE COORDINATION (CASE MANAGEMENT)

ISSUE

Children and adults with mental retardation must be able to take advantage of the multiple resources and services available to all other citizens. However, finding and coordinating these resources to meet the entire range of personal needs and preferences necessary to assure quality of life in the community is not an easy task for anyone. When mental retardation is a factor, special assistance in planning and carrying out the individual service coordination process may be required.

The quality of individual service coordination can be adversely affected by excessive case loads, conflicts of interests, responsibility that is not equivalent to authority, lack of training and uniform practice, inadequate pay, insufficient clerical support and excessive paperwork. The effectiveness of individual service coordination is affected by inadequate fiscal and programmatic resources.

POSITION

The ARC believes that:

- Individual service coordination (sometimes called case management) is a distinct social service that enables people with mental retardation and their families to find, utilize and coordinate available resources and opportunities in their communities on the basis of individual need.

- All children and adults with mental retardation and their families should have access to the services of a service coordinator to assist them at the level they need and desire or to support families or individuals serving as their own service coordinators.

- Individual service coordinators should be well-trained and know both the community and the individuals and families. They should be competent, sensitive and committed to representing the interests and preferences of the individual and/or family. They must provide reliable information, help explore options, coach individuals and families and guide in making informed decisions and gaining access to services and supports. They also should assist in the coordination of service providers to work with the individual toward consistent goals which reflect the personal needs and wishes of the individual.

- Each individual service coordinator should take responsibility for promoting the development of the full array of services needed in the community and should report gaps identified to bodies responsible for program planning and development.

- Service coordination should be independent of providers of services to ensure that service coordinators are free to advocate based on the preferences and needs of the individual rather than the needs or constraints of the service providing agency.

- Services should be developed around the individual and family rather than trying to fit them into existing services merely because of availability.

- Service coordinators should utilize and strengthen formal and informal resources. Informal resources include family, friends, co-workers and neighbors.

- The number of individuals served by each service coordinator must be kept to a minimum in order to assure the service coordinator the opportunity to establish strong working relationships with individuals and families. Variables which must be considered when establishing that number include level and intensity of need, geographic location, crisis situations and age of individuals.

- It is in the public interest that people with mental retardation be integrated into their communities. Therefore, public funds should be made available at appropriate levels to support the essential function of individual service coordination that is of high quality as measured by effectiveness, responsiveness, continuity, reliability and acceptability to the user.

Adopted by Delegate Body
November 10, 1990

INTEGRATION

ISSUE

People with mental retardation should be integrated fully into the ordinary life of their communities. Integration enhances their opportunities for human development. It increases their opportunities for association with and acceptance by nondisabled people. Integration gives children and adults with mental retardation and their families appropriate opportunity to make choices in their daily lives. It serves as a fundamental guide in shaping laws and policies that affect persons with mental retardation. Integration avoids the demeaning and stigmatizing effects of segregation.

"Segregation is the way in which society tells a group of human beings that they are inferior to other groups of human beings in that society." (Testimony of: Kenneth Clarke, Brown V. Board of Education, 1956.)

POSITION

The Association for Retarded Citizens believes that integration means all children should have the right to:

- live in a family
- grow up with their nondisabled peers in their communities
- be educated in their neighborhood schools with their friends
- receive an education that will prepare them to live and work in the real world
- play and participate in recreational activities with non-disabled peers.

The ARC believes that integration means all adults should have the right to:

- be contributing members of the community
- engage in work and be paid for it
- choose their own friends
- choose to live alone or with their families or friends in the community
- participate in recreational activities with nondisabled peers
- fully exercise their rights and responsibilities under the Constitution of the United States.

Adopted by Delegate Body
October 6, 1989

SELF-ADVOCACY

ISSUE

Self-advocacy means acting and communicating for oneself. For most people this is a skill that is acquired as one matures from infancy through adulthood. People with mental retardation may need help in acquiring this skill through training, experience, practice or opportunities which allow people to make decisions regarding their own lives.

Our society historically has considered individuals with mental retardation incapable of self-determination and relegated them to a subordinate or dependent role. Individuals with mental retardation speaking and choosing for themselves is a new concept that has not been readily embraced by the community.

Self-advocacy provides people one means to become active recognized participants in society. It also not only changes their own lives, but helps members of the community to view those with disabilities in a positive light, as people of equal value and worth. People involved in self-advocacy strive to express themselves regarding their preferences, make many of their own choices, take responsibility for their decisions and actively involve themselves in the community. Self-advocates gain independence by directing their own lives.

POSITION

The ARC views self-advocacy as vital in continuing to improve the quality of life for all people with disabilities. To be successful, self-advocacy should continue to take place at the individual and system levels. At the individual's level, the ARC believes that:

- All children and adults with mental retardation regardless of the extent or severity of the disability, should be allowed, supported and encouraged to make decisions about their lives. This includes understanding the responsibilities associated with the exercising of rights, and the consequences of misuse of those rights.

- Self-advocacy is a lifelong process. People involved in self-advocacy should be encouraged and given the opportunity to constantly grow and strive for more independence and self-determination.

- Language is important in how people view and feel about themselves and others. Terms which promote self-esteem and self-worth should be used in addressing or describing people with mental retardation. Therefore, only the use of people-first language is acceptable.

- People with mental retardation should be encouraged to use and develop their abilities in problem solving, decision making and other areas that will ultimately assure them more control of their lives. Families, professionals and others should be available to provide thorough, objective and clear information on choices and possible consequences of each choice.

- People usually respond and act in the manner in which they are treated. Therefore, people with mental retardation should be treated in a respectful, age-appropriate manner, as one would treat people without such disabilities.

At the systems level, the ARC believes that:

- Self-advocacy groups should be encouraged to form, select leaders, meet regularly and define their agenda. Interested individuals should be available to assist with the formation and running of self-advocacy groups, while being careful not to take control of the group or project their biases upon the group.

- The ARC should encourage and provide appropriate accommodations so that people with mental retardation can take an active role in all aspects of membership, employment and leadership of the ARC. By example, the ARC can provide leadership to other organizations to include people with mental retardation.

Adopted by Delegate Body
November 10, 1990

SEXUALITY

ISSUE

Sexuality is a natural part of every person's life. Sexuality and sexual expression of people with mental retardation create diverse reactions. This issue requires respect, understanding, caution and an awareness of the wide array of human rights. Current social trends make the issue more urgent and complicated. The commitment to full integration into the community has given people with mental retardation new experiences, more risks, and more opportunities to make choices. The ability to make educated choices in the area of sexuality is especially critical.

POSITION

The ARC recognizes and affirms that individuals with mental retardation are people with sexual feelings, needs and identities, and believes that sexuality should always be seen in the total context of human relationships. Sexuality includes gender identity, friendships, self-esteem, body image and awareness, emotional development and social behavior, as well as involvement in physical expressions of love, affection and desires.

The ARC believes that people with mental retardation have the right on an individual basis to:

- o have privacy;
- o love and be loved;
- o develop friendships and emotional relationships;
- o choose friends;
- o learn about sex, sexual problems, sexual abuse, safe sex, and other issues regarding sexuality;
- o exercise their rights and responsibilities in regard to privacy, sexual expression, and the "pursuit of happiness"; and
- o marry and have children.

The ARC supports programs which encourage people with mental retardation to develop expressions of their sexuality that reflect their age and social development, acknowledge the values of their families and are socially responsible. The ARC believes education should be available for people of all ages to assist in and, where appropriate, teach expressions of sexuality and responsible sexual behaviors with respect for the rights of others.

In support of this position, ARC will advocate that the person with mental retardation be educated and receive proper supports to protect him/herself from abuse, exploitation, unwanted pregnancy and sexually transmitted diseases while safeguarding dignity and rights.

The ARC further advocates that on an individual basis people with mental retardation have the right to receive sex education, to marry, to have children if they so desire, and to receive proper supports to assist them in rearing their children. Furthermore, the ARC believes that the presence of mental retardation regardless of severity, must not, in itself, justify either involuntary sterilization or denial of sterilization to those who choose it for themselves.

Adopted by Delegate Body
November 10, 1990

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Association for Retarded Citizens

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EDUCATION

ISSUE

The Education of the Handicapped Act provides that all children with disabilities, including mental retardation, be educated to the maximum extent possible with students who are not disabled. Recognizing the statutory mandate as a minimum standard, the education of students with disabilities has moved beyond the narrow interpretation of least restrictive environment to the concept of inclusive education.

However, problems of segregation persist for students with mental retardation. They may not have access to the same programs and services provided to other students. Their curriculum may be outdated and not based on their individual needs. They often leave schools to face unemployment, underemployment and waiting lists. Their education programs are underfunded and lack sufficient trained personnel. They are overlooked in today's educational reform movement.

POSITION

Fundamental Principles

- All schools should value all students and include them in all aspects of school life.
- Preparation for life in the community best occurs when all students of different backgrounds and abilities learn and socialize together in classrooms and other school settings where all have a chance to achieve and receive instruction designed to develop and enhance successful living within the community.
- Each student with a disability belongs in an age appropriate classroom with peers who are not disabled.
- Each student has the right to receive individualized education which provides choices, meets the student's needs, and offers the necessary support.
- Quality education should value and address the concerns of the student and the student's family.

The basic goals of education should develop:

- Increased competency and interdependent functioning;
- Self-esteem;

- Relationships with people in the community;
- Skills and competencies which enable students to contribute to the communities in which they live.

o All students should receive instruction which facilitates an understanding and acceptance of human differences.

o Educational programs must be sensitive to linguistic and cultural differences as well as family situations.

o Early intervention services must be provided in accordance with the individualized family service plan. These services should be offered in integrated settings with infants, toddlers and preschoolers.

Principles of Daily Experiences

o Each student should have the opportunity to follow the same daily schedule as followed by all students in their neighborhood school.

o Each student should have the opportunity to participate in recreational and extracurricular activities with appropriate support and supervision by school personnel.

o Each student should be encouraged and supported toward developing meaningful social interaction and friendships with all other students.

o Related services such as speech, physical or occupational therapy should be provided at a level and in a manner that supports development of the individual student in accordance with the student's needs.

o Educational agencies must provide transportation services that allow students with mental retardation to participate in all school activities on the same scheduled basis as provided to all other students.

Principles of Choice and Rights

o Legal rights of students and families must be protected, supported, enhanced and expanded.

o Students should receive instruction and experiences in making choices and decisions and in exercising responsibility as citizens.

o Student and family concerns about the quality of their educational program should be taken seriously, and addressed in a fair and objective manner.

Principles of Systems Change

- Regular and special education teachers, administrators and support staff should merge together as a team with the student and the family to meet the unique needs of each student.

- School districts must offer program content, resources and support in all phases of the educational experience in order to fully include all students.

- Program evaluation must be based on outcomes and include in the process all providers, their representatives and advocacy organizations as well as families and students.

- Teachers, administrators and all other school personnel must receive preservice and/or inservice training to increase their knowledge, acquire skills and improve their attitudes to ensure the provision of educational experiences consistent with these principles.

- Institutions of higher education and state certificate granting agencies must alter their course offerings and certification requirements to ensure that all personnel seeking employment in the public schools are effectively prepared to be willing and able to bring their skills to bear on the education of students with mental retardation. In addition, educational accrediting bodies must adopt and assess accreditation criteria that assure the delivery to students with mental retardation of education programs that are consistent with these principles.

- Funding must be provided to provide extended school year programs that meet individual needs.

- Transitions that occur from early intervention to schools and from schools to adult life occur successfully when there is early planning and involvement of all agencies and the family, coordination and follow-along, and a commitment to successful outcomes for the individual.

The ARC recognizes that to achieve these principles for students with mental retardation and all other students, additional resources are required. Therefore, the ARC is committed to working independently and with others to fulfill these needs.

It is the belief of the ARC that while the achievement of the goals presented in this position statement will significantly and positively enhance the quality and impact of the education received by all students with mental retardation, the ultimate effect will be to substantially improve the education of all students.

Adopted by Delegate Body
November 10, 1990

EMPLOYMENT

ISSUE

The vast majority of adults with mental retardation are either unemployed or underemployed, despite their ability to take part in meaningful work in the community. Many of these individuals are in sheltered settings for an indefinite period of time. Often only those who can participate in the regular workforce without any on-the-job support are given the opportunity to work in business and industry. Today, employment programs designed to assist individuals with significant disabilities are being developed but do not yet meet the growing need.

POSITION

The ARC believes that the vast majority of people with mental retardation can be employed. With new knowledge and technology, even more people with mental retardation will be considered employable. In addition, with appropriate education, training and support, these workers can be fully integrated into settings where they will receive equitable wages and benefits, including retirement programs for work performed. They will, therefore, contribute to their own independence and to the value of their community.

The ARC believes that for students, education for employment should:

- include training that would allow them to be employed as adults;
- occur in a variety of actual work settings which offer opportunity for integration with co-workers without disabilities;
- provide instruction regarding principles of career choice, advancement, and change; and
- provide for the transition from the world of education to the world of work.

Further, the ARC believes that for adults:

- vocational assessment should be available and based on actual work experiences that reflect individual interests and choices.
- opportunities for career development, lifelong learning and retirement planning must be provided to workers with mental retardation from school-age through adulthood, with business, government, public and private education and labor each playing an important partnership role in providing meaningful training opportunities.

- services supporting employment should be flexible and based on individual need and should include, but are not limited to transportation, on-the-job assistance, therapies, financial planning, follow-along and advocacy.

- employment should occur in a variety of work settings with an emphasis on the greater use of natural supports such as co-workers.

- wages and benefits should be based on production, work quality and other factors commensurate with those used to compensate co-workers without disabilities.

- retirement should be an option for all.

The ARC believes that at the system level:

- disincentives should be removed in existing public policies to enable employees with mental retardation to obtain increased earnings, rights and benefits.

- funding, training and technical assistance must be available to current vendors of services to enable conversion of traditional services to the provision of employment in integrated settings.

The ARC is committed to achieving adequate funding and resources to accomplish these goals.

Adopted by Delegate Body
November 10, 1990

RESIDENTIAL LIVING ARRANGEMENTS

ISSUE: In-Home Support

The majority of children and adults with mental retardation live in their own homes, but less than one percent of all residential funds are used to provide direct in-home support services. Families who maintain a child or adult at home are often required to provide continuous care and supervision over extended periods of time, some of which can be alleviated by provision of financial resources, specialized services, respite, technological devices and structural modifications to increase accessibility of the home. Some adults with mental retardation, capable of living in their own homes, require in-home supports as well.

One of the most critical elements required to assure that people with mental retardation remain in their homes is a crisis intervention capacity, preferably provided in the person's own home. This service must be developed if unnecessary out-of-home placements are to be avoided. All of the services described above are primarily available through out-of-home placement since current public policy is designed to encourage the funding for such services in out-of-home settings.

POSITION

All children need a home with parents or caregivers who provide an atmosphere of love, affection, security and comfort. Some adults may choose to stay in their parents' home, and the parents may support that choice. Other adults want to have a place of their own, with supports if necessary. They need housing that is safe and affordable.

Public funding should enable adults to live in, rent or buy, their own homes. Both children and adults should receive individual and family support which is designed to encourage independence, productivity and integration, and should be of an intensity required by each person's unique needs.

ISSUE: Out-of-Home Support

In the past, there has been a belief that people with severe disabilities must earn the right to lead integrated lives in the community. It is commonly acknowledged that small community-based living arrangements are effective for all people with mental retardation, including those with the most severe mental retardation, behavioral or physical disabilities.

Conversely, it is well documented that institutional environments have many and serious adverse effects. They have demonstrated a lack of success in providing essential opportunities for growth and development needed by persons with mental retardation. They are especially detrimental to children. There continues to be a bias of public funding directed toward supporting institutions rather than family size residential services. It is time to reverse this bias.

POSITION

The Association for Retarded Citizens advocates for public policy changes and full funding to support the development of community-based residential programs for persons with mental retardation to grow, develop and enjoy life.

The ARC further believes that:

- all persons with mental retardation have a right to live in their local communities with nondisabled citizens;

- community-based residential services for persons with mental retardation should be designed to meet the needs of the individual.

The ARC's policy supports the phasing out of those services, activities and environments which:

- inappropriately remove children and adults from their homes and neighborhoods;

- require that persons with disabilities live under circumstances that would not be considered acceptable for persons within the same age range when they are not disabled; and

- prevent or hinder normalized social support networks, family systems, peer relationships and friendships.

During the phasing-out process, quality care must be assured for persons residing in such living environment.

Adopted by Delegate Body
October 6, 1989

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Association for Retarded Citizens

XIII

BEHAVIOR INTERVENTION

ISSUE

Behavior intervention programs include a variety of techniques to develop and maintain skills that will enhance an individual's opportunities for learning and achieving independence. The Association for Retarded Citizens supports the development and use of positive behavior intervention programs in meeting individual needs, while prohibiting and preventing the use of procedures that may cause physical or psychological harm or are dehumanizing. Specifically, the use of aversive and deprivation procedure [1] is in direct conflict with the right of people with mental retardation to be free from harm. These procedures cause a loss of dignity and inhibit full participation in society.

POSITION

Prior to consideration of any behavior intervention program, the nature and extent of the perceived behavior problem and what the person is trying to communicate through this behavior must be determined. Contributing factors such as physical or medical conditions, social influences, living arrangements, work setting and inappropriate programming must be reviewed and addressed prior to development of a behavior intervention program through a comprehensive functional analysis. [2]

For individuals with mental retardation, the ARC supports behavior intervention programs that are:

- designed and applied in a humane and caring manner with the ultimate goal of growth and development;
- based upon a formal functional analysis and thorough assessment of each individual's existing competencies and characteristics;
- based on procedures adequately documented in the clinical/educational research literature;
- intended to replace challenging behavior with adaptive and socially productive behavior;
- implemented in positive and socially supportive environments;
- carried out by staff who have been trained and are qualified to effectively apply positive, nonaversive approaches;
- monitored continuously and systematically to ensure that the approach is consistent with individual needs and successful in achieving established goals and changed in a timely fashion if success is not evident or occurring at an appropriate rate.

Further, the ARC calls for the elimination of any aversive interventions that withhold essential nutrition and hydration, inflict pain, use chemical restraints in lieu of programming, or impose techniques which produce physical or psychological pain, humiliation or discomfort. All means of review processes, including human rights committees independent of service providers, should be used to monitor the quality of ongoing programs and make necessary adjustments. Extraordinary measures should be taken (if necessary) to ensure the success of positive interventions.

1 Aversive refers to noxious, painful, or intrusive stimuli or activities applied in response to challenging behavior, including, but not limited to, ammonia spray, contingent electric shock, water spray to the face, seclusion, etc. Deprivation refers to such actions as withholding, withdrawing, or delaying visitation or private communication with family and friends, adequate sleep, shelter, bedding, bathroom facilities and food or drink.

2 A functional analysis involves the observation of how a behavior is affected by both internal (e.g., illnesses) and external (e.g., social interactions) influences.

Adopted by Delegate Body
October 6, 1989

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Association for Retarded Citizens

XIV

GUARDIANSHIP

ISSUE

The majority of adults who are mentally retarded can manage their own affairs with informal assistance and guidance from family, friends, citizen advocates, and service agency support personnel. The adult acting on his own behalf must have some ability to foresee and appreciate future consequences of present-day decisions, actions or failure to act. Consequently, some persons may require the more formal protection and assistance provided by a guardian who is appointed by a court and is legally empowered to act on their behalf. This need will vary from requiring assistance in limited areas -- for example, financial planning or management -- to, for a very few, full guardianship of the person and property.

POSITION

The appointment of a guardian or trustee is a serious matter involving the deprivation of a person's independence and rights. The ARC believes the decision should be made only to enhance rather than limit a person's ability to exercise his or her rights. Appointment of a guardian should be made only to the extent necessary for the welfare of the individual and not for the convenience of the family, the service system, or society.

Each state should adopt procedures allowing a range of limited guardianships. The restrictions on the ward's rights and decision-making powers should be confined to those areas in which the ward is demonstrably incapable of appreciating the serious consequence of his or her decisions or lack of foresight.

In appointing a guardian, the courts should consider those qualities needed by the guardian to fill this role effectively. Those qualities would minimally include an understanding of mental retardation and the individual and an ability to relate to the ward so as to understand and represent his or her needs and desires effectively. Barring evidence to the contrary and if they so choose, parents should be viewed as qualified and concerned guardians for their adult offspring who are mentally retarded.

The ARC believes the continued necessity for guardianship should be evaluated annually, and at all times guardians should encourage their wards to exercise choices for themselves even in those areas where the guardian has authority to intervene. Since guardianship represents a transfer of the responsibility for exercising an individual's rights, adequate safeguards are needed to assure the

individual retains as much independence as possible. Guardians should be accountable to an appropriate authority to ensure that abuse does not occur. At the same time, a legal system must not be so cumbersome or intrusive as to limit the guardian's ability to respond to the ward's daily needs in a timely and normal manner. Formal judicial review of specific decisions should occur where the consequences of a decision are of major importance or are irreversible.

Adopted by Delegate Body, 1983
Adopted by Board of Directors, 1984

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Association for Retarded Citizens

XV

PREVENTION

ISSUE

Mental retardation affects all major areas of life such as social, educational, health, and economics. While knowledge of both the causes and ways to prevent mental retardation has grown enormously, comprehensive programs for prevention are not consistently implemented. Comprehensive programs must include the application of biomedical advances, public education, access to health care, and the elimination from our environment of hazards which cause mental retardation. Equally important is the support of research into causes of mental retardation and its prevention. The development of methods to alleviate the impact of mental retardation must also be continued and expanded.

The known and suspected causes of mental retardation operate primarily in the early periods of life:

- Before conception and during pregnancy, the parents' genetic makeup, metabolic disorders, environmental contaminants, diseases and infections, and social conditions, including poverty, substance abuse and inadequate prenatal care, affect reproduction and the development of the fetus.

- At birth, complications of delivery and conditions of the newborn (such as prematurity or low birth weight) are known to affect brain development and to increase the risk of impairment.

- During childhood, diseases and illnesses, malnutrition, lead poisoning, abuse and neglect, and injuries may result in mental retardation.

POSITION

The ARC is committed to reducing the incidence and limiting the consequences of mental retardation through education, research, advocacy and by support of families, friends, and the community.

The ARC believes that every person has the right to grow and develop in nurturing environments that are free from abuse and neglect, free from disease, and safe from injury.

Coordinated and expanded programs and research must be established by the government and the private sector to prevent mental retardation.

Included in these efforts should be:

- o the availability and provision of immunization against Rubella, measles and other contagious diseases prior to pregnancy;
- o the availability and provision of genetic counseling;
- o increased educational programs and materials on the risks of exposure of the fetus to dangers such as X-rays, smoking, alcohol and drug use, non-prescription medications and prescribed medications;
- o adequate and available prenatal care, including nutrition;
- o education regarding the impact of sexually transmitted diseases on the unborn fetus;
- o mandatory funded newborn screening programs for metabolic disorders such as phenylketonuria, galactosemia and hypothyroidism;
- o mandatory use of seat belts, safety seats and helmets;
- o education regarding the risks of the use of aspirin with children;
- o availability of competent perinatal and post natal care, including frequent physical/developmental checks and adequate nutrition;
- o mandatory immunization of children for all preventable, contagious diseases;
- o education designed to prevent childhood injuries such as falls, drownings, and poisoning;
- o removal of environmental contaminants which lead to conditions such as lead poisoning;
- o enforcement of existing public policy (i.e. prohibition of lead based products).

The ARC believes that all of the above preventative measures should recognize the existence and potential barriers of language, cultural differences and illiteracy to understanding and implementation of prevention programs.

Further, the ARC supports increased funding for research into causes, prevention and additional methods to alleviate the impact of mental retardation.

Adopted by Delegate Body
November 10, 1990